

NIH Comprehensive Strategic Plan and Budget To Reduce and Ultimately Eliminate Health Disparities

IC MISSION/VISION STATEMENT

The Warren Grant Magnuson Clinical Center is the research hospital of the National Institutes of Health (NIH). Through clinical research, scientific discoveries in the laboratory are translated into new and better medical treatments and therapies.

Clinical research is at the heart of the Clinical Center's mission. Natural history studies, often in patients with rare diseases, make up about half of the clinical research conducted here in Bethesda, Maryland. Understanding the basis for rare diseases often leads to new approaches to common problems. Most of the other clinical research studies are the early (Phase 1 and 2) trials that are the first applications of basic, bench-side research into new treatments and therapies in people. Approximately one thousand protocols are under way at the Clinical Center.

OVERVIEW OF THE IC STRATEGY FOR ADDRESSING HEALTH DISPARITIES

The Clinical Research Center is the clinical research facility of the National Institutes of Health. It provides patient care, services, training and the environment in which NIH clinician-scientists creatively translate emerging knowledge into better understanding, detection, treatment and prevention of human diseases for the health of a diverse nation.

The NIH Clinical Center will serve as a premier center for clinical research. A model of collaborative excellence, the NIH Clinical Center will lead through innovation in the design, conduct, training, and impact of clinical research.

Attached, in priority order, are the areas of emphasis from the Clinical Center Strategic Plan on Reducing Health Disparities. You will note that the substance of the plan is consistent with the CC mission that is *support* for, rather than *conduct* of clinical research. The priorities outlined in this plan fall into the categories of Infrastructure & Public Information/Outreach.

Priorities 1 and 3 are contingent on receipt of funding from the National Center on Minority Health and Health Disparities.

OBJECTIVES:

Priority I. Infrastructure and Cross-Cutting Issues

Goal: Tailor Aspects of Patient Recruitment and Referral Process to Facilitate Minority Participation in Clinical Trials.

Improve Patient Recruitment and Referral Process

The NIH Clinical Center (CC) established a Patient Recruitment and Public Liaison Office in 1997 to support the Institutes in their individual efforts at patient recruitment, including minorities, to clinical research protocols. The office serving as the CC's central location for the dissemination of protocol information, is responsible for ensuring easy and equitable access to the organization and its services.

Actions:

- Maintain ethnically diverse staff in the Patient Recruitment and Public Liaison Office to deal with cultural differences sensitively and appropriately.
COMPLETION DATE: FY2002 Ongoing FY2006.
- Evaluate minority recruitment strategies by tracking the number of minorities who contact the PRPL annually and are referred and enrolled in a protocol.

Completion Date: FY2002 Ongoing Through FY2006.

Completion Date: FY2006

Outcome:

- **Improve response time for requirement for interpretive services.**
- **Appropriate documentation of Informed Consent forms (for most frequently requested languages).**

Priority 2: Ensure Needs of Minority Patients are Met Through Increased Recruitment of Minority Blood and Marrow Donors.

Individuals of non-Caucasian ancestry have tissue antigen types (HLA or human leukocyte antigens, also known as transplantation antigens) that are substantially different from the HLA types of Caucasian persons of European descent. HLA compatibility is important in obtaining compatible platelet transfusions for patients who are alloimmunized, and in finding HLA matched unrelated bone marrow donors for patients awaiting hematopoietic transplantation. In particular, persons of African American or Asian ancestry are much more likely to find a matched blood or marrow donor among individuals of the same ancestry. This is one of the highest proportions of minority donors in any NMDP Center in the country.

Similarly, the red cell phenotype (characteristic antigens on the surface of the red blood cell) of African Americans differs substantially from that of Caucasians. African transfusions are frequently only able to find compatible red cell units from donors of the same ethnic background.

Completion Date: FY2003

Outcome:

- Establish a recruitment program targeting HLA-typed plateletpheresis donors of minority background.
- To increase the number of transplants performed on minority patients awaiting transplantation.
- To increase the percentage of minorities participating in the plateletpheresis donor program.

Priority 3. Limited English Proficiency (LEP) Program/Service Center

The CC Volunteer Interpreters Program has exceeded its ability to address the needs of the Spanish speaking and other LEP patients. Current services provided by 32 Spanish speaking volunteers and one (1) HACU student include: assistance with admissions, orientation to the CC and NIH, interpreting during family and medical team meetings with patients, and assistance during medical procedures. The need is most pressing for interpreting informed consent documents and in fulfilling STAT requests for services. The provision of a dedicated program will ensure that informed consent and equal access rights of patients are addressed and the accompanying liability and ethical concerns are alleviated. In addition, patient confidentiality issues expressed and substantiated by the CC Patient Advisory Group about family members and other patients interpreting for the medical team, will be addressed.

Increased resources to this program will ensure attention to multiple issues faced by the CC such as:

- Hire two (2) interpreters. **Completed FY2002.**
- Address minority and health disparity issues and services to meet Federal LEP requirements and uphold the NIH mission regarding recruitment of women and minorities. **Completed FY2002.**
- Provide a systematic process for analyzing the interpreting service needs for languages not currently met (such as Romance, Slavic, and Arabic languages). **Completed FY2002.**
- Ensure the translation of protocol, informed consent, and other written documents. **Completion Date Spring FY2003.**
- Ensure appropriate bilingual/trilingual signage in new Clinical Research Center. **Completion Date FY2004.**

Priority 4. Establish a Hospital Environment in which the Diverse Needs of Minority Patients are Recognized and Addressed.

In the healthcare industry there remains a history of underrepresented minorities in professional positions. In order to successfully address this disparity, the number of health care providers of diverse backgrounds must increase so that the needs of patients are appropriately met through individual interactions with health care providers with whom they are easily able to identify. Once the number of minority employees in professional positions increases, there must be a plan to retain them and provide equal access to educational and career opportunities.

Actions:

- Recruit and retain a workforce that represents the diversity of our nation by:
- Building relationships with academic and professional organizations to recruit a diverse workforce. **Completion Date FY2003.**
- Developing a targeted recruitment plan for occupations with significant under-representation of minorities. **Completion Date FY2003**
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Completion Date: FY2003

Outcome:

- **Diverse workforce accomplished as reported by labor/statistics/census data.**
- **Establishment of a referral mechanism to the CC for Minority professional and academic organizations.**

Priority 5. Public Information/ Outreach

Goal: Continue Active Public Information/Outreach Program About the NIH Clinical Center and Participation in Clinical Trials.

Initiative A: Increase awareness of the Clinical Center among Minority Patients and referring physicians.

Initiative B: Enhance Community Involvement in Minority Outreach

Actions:

- Continue informational meetings with with professional organizations such as the National Medical Association and Hispanic Medical Association.

Completed: FY2002

Outcome:

- **Improve awareness of Clinical Center and NIH as a referral source for educational, community and professional organizations.**

Priority 6: Enhance Community Involvement in Minority Outreach

Actions:

- Establish a network of community advocates through the development of a Community Leadership Alliance, consisting of leaders from minority organizations, to assist the NIH Clinical Center in reaching out to and understanding the needs of minority populations.
- Conduct presentations at minority community organizations to address issues of concern related to participation in research.
- Disseminate information about the NIH Clinical Center and participation in clinical research to: corporations who employ a diverse workforce; minority businesses; and, minority education and church groups.
- Establish ongoing working relationships with minority professional healthcare organizations such as the National Medical Association.

Completed: FY2002

Outcome:

- **Increased referral of Minority patients by organizations such as NMA and self referral as a result of outreach to community organizations and churches.**

Priority 7. Design Outreach Effort to Provide Lay Community with an Understanding of How Clinical Research is Addressing Health Disparities.

Actions:

- Plan “Medicine for the Public” lecture series in collaboration with the Institutes to target lectures to areas of research in health disparities.
- Distribute “Medicine for the Public” information to minority schools, community groups, health fairs, and health-care facilities.

Completed: FY2002

Outcome:

- To make available the “Medicine for the Public” lecture series available via video tape and teleconferencing to minority health schools, community groups, etc.

Priority 8. Public Information/Outreach

Goal 1: Establish Active Public Information/Outreach Program about the NIH Clinical Center and Participation in Clinical Trials.

Focus group research conducted by the NIH Clinical Center demonstrated that national and local awareness about the NIH Clinical Center, especially among minorities, is low. People are unaware that the NIH Clinical Center is a research hospital or, they are under the impression that research is conducted only on rare or terminal illnesses. Additionally, minorities have many negative perceptions regarding participation in clinical research. An outreach and education effort, employing multiple outlets (community presentations, internet and the media) is critical to increase public awareness about the NIH Clinical Center, correct misinformation, and foster positive perceptions.

Initiative A: Enroll Minorities in Education and Training Programs in Clinical Research

Research on health disparities requires increasing numbers of minority physicians leading clinical trials. To facilitate this goal, the NIH Clinical Center will make a concerted effort to enhance enrollment of minorities in its clinical research curriculum. Since 1995, the NIH Clinical Center has offered a training program in clinical research, *Introduction to the Principles and Practice of Clinical Research*. Throughout the past five years the scope of the curriculum has expanded and participants now attend the program both in person and via satellite broadcasts (with five locations including the University of Puerto Rico). Enrollment has increased exponentially each year. In addition, three other courses are now sponsored by the NIH Clinical Center. An experiment in distance learning designed to strengthen training opportunities in clinical research is a degree-granting collaboration between the NIH Clinical Center and Duke University. In its fourth year, this course is designed primarily for clinical fellows and other health professionals who are training for careers in clinical research. A second course, the *Principles of Clinical Pharmacology*, also in its fourth year, is based on a series of lectures covering the scientific basis of the discipline of clinical pharmacology. This course is teleconferenced to three sites. The third course, *the Ethical and Regulatory Aspects of Human Subjects Research* offers education and training in research ethics for intramural scientists and research staff.

Action:

- A partnership with the Medical Sciences Campus at the University of Puerto Rico (UPR) has allowed videoconferencing of this course to 87 students in San Juan. Traditionally, the Medical Sciences Campus at the UPR has been a teaching and service-providing institution. Efforts are being redirected to further develop clinical research at the UPR, and the broadcast of this course allowed

investigators to focus on clinical research training. This collaboration is planned to continue with expanded enrollment as determined by UPR faculty.

Completed: FY2002

Outcome:

- To increase the number of minority medical students involved in the *Introduction* to the Principles and Practice of Clinical research.

CC Health Disparities Budget
(Dollars in Millions)

Institute / Center	FY 2002			FY 2003		
	Research	Infrastructure	Outreach	Research	Infrastructure	Outreach
CC	\$0.00	\$0.60	\$0.60	\$0.00	\$0.60	\$0.60

Clinical Center figures for FY2002 and FY2003 were not included in original estimates in the FY2003 President's Budget and are therefore shown as non-add.